

Autism and Anxiety

From stress to success!



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Youth Advocate Programs



Purposes of This Training

- Identify the **signs and symptoms** of anxiety, and explore the experience through the words of self-advocates
- Understand the **"brain basis"** of anxiety, and its connection to the sensorimotor challenges of the autism spectrum
- Recognize the factors that can **trigger and intensify** anxiety, and consider practical strategies to reduce their impact
- Consider a wide range of approaches that can help people with autism become more **self-aware and resilient** in the face of stress
- Explore socially valued activities that respect and use the **positive aspects** of vigilant behavior to achieve desired goals

Imagine....



Lurking danger...

A vigilant youth...



A long-ago scene
around the camp fire...



3 responses to danger:

- **Fight!**
- **Flight!**
- **Freeze!**



What is **anxiety**?

- A **hard-wired alarm system** in the brain, protecting us from **life-threatening dangers**



- With fewer real dangers, now it is triggered by **perceptions of SOCIAL danger**

"Hard-wired"?



- Do we run because we're afraid?
- Or are we afraid because we run?



- Emergence of body changes due to threatening stimuli: *measured in milliseconds (thousandths of a second)*
- Emergence of a single, simple thought: *measured in seconds*



Anxiety Disorders



- Officially classified 1980:
 - Panic Disorder
 - Social Phobia
 - Specific Phobia
 - Post-Traumatic Stress Disorder (PTSD)
 - Obsessive-Compulsive Disorder (OCD)
 - Generalized Anxiety Disorder (GAD)
- May have more than one at a time
- Often accompanied by depression

GAD Symptoms



- Excessive, ongoing worry and tension
- An unrealistic view of problems
- Restlessness or "edginess"
- Irritability
- Muscle tension
- Headaches
- Sweating
- Difficulty concentrating
- Nausea
- Frequent need to go to the bathroom
- Tiredness
- Trouble falling or staying asleep
- Trembling
- Being easily startled

Who has seen the Temple Grandin biopic?

- What causes of **stress** or signs of **anxiety** did you notice?
 - Intensity?
 - Sensorimotor challenges?



People with autism can have **too much** or **too little** input from



- Vision
- Hearing
- Smell
- Touch
- Taste
- Proprioception
- Vestibular processing

Proprioception



- **Body awareness**: knowing where our body parts are in space and in relation to each other, to carry out coordinated movements
- May fluctuate and be unreliable

Vestibular processing

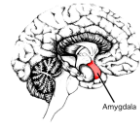


- Centered on the inner ear; involves ability to maintain **stability, posture, orientation**
- Malfunction leads to lack of balance, unstable visual field; movements of people and objects seem confusing

Brain Basis

• **Hyper-connectivity**

- Amygdala: primary role in formation and storage of **memories associated with emotional events**, from fear to happiness



• **Hypo-connectivity**

- Cerebellum: vital to **motor learning**, equilibrium, and posture; also has role in attention, language, and sensory regulation



Is it possible to have
"too much brain"?!



Too much meaning/connection

Just right - safe, capable, interested

Too little meaning/connection



Hyper-connectivity: The Amygdala

- Amygdala (primary roles in forming and storing memories of emotional events) is significantly **enlarged**
- Extra neurons (brain cells) = **hyper-connectivity in key brain areas**
- Atypical neurons arrangements exist **before birth**
- Brain networks for reacting and inhibiting reactions are **delicately balanced**, easily disrupted
- Neuron connectors (synapses and dendrites) have unusual form, function; disrupted connectors may lead to **seizures**



Hypo-connectivity: The Cerebellum

- Research: 40-50% **fewer** cerebellar Purkinje cells in individuals with autism
- Typically, these cells specialize for motor functioning, sensory regulation, speech, attention; fewer cells means they may have to **multi-task**
- When multitasking **cells get conflicting demands**, the person may have difficulty performing motor, sensory, attentional activities

- **Cerebellum**: part of the brain that "takes over" when movements become **habitual or automatic**
- **Research**: when practicing a task, activity in the cerebellum increased **less** in children with autism than in neurotypical children. Children with autism had **greater** activity in the higher brain region that exerts "**top-down**," **voluntary control** over movement
- **Meaning**: typically developing children can rely more on motor habits; children with autism must rely more on willful control of movement

• **This is exhausting!**



How do

*"ramped up" connections in the
emotion-processing part of the brain
slower, less automatic connections in
the movement regulation area
impact everyday experience?*



In the words of a self-advocate...



*"My brain always gets there in the end.
It's just that it takes the scenic route!"*

-- Barbara Moran



Sensory Reactivity: hypo and hyper

1. NON-FIRING (of nerves and neurons in sensory system) - person *not getting feedback*, not perceiving or connecting with feelings

- *"Everyone chattered about school but I couldn't really hear them -- there was a kind of hum inside me that I later realized was happiness."* -- Sean Barron, "There's a Boy in Here"

- "I think my son experiences the world like a person in a *space suit*."

» a parent

- "My body *goes away*."

» a person with autism



2. OVER-FIRING -- person is hyper-sensitive to sensation, has *overwhelming* sense of self and of others (e.g. caution feels like terror, happy feels like manic)

- "Too good!"

-- Jessie Park in "The Siege"



*"How can I practice self-control when there is *so much* self to control?!"*

- Barb Moran



3. MIS-FIRING - emotion is felt, but the brain **hasn't processed its context** (e.g. physiological responses of affection, such as deep breathing and rapid heart rate, are misread as responses to danger, resulting in aggression against a person one likes)

-- Donna Williams, self-advocate and author



NOTE: This condition also occurs in victims of post-traumatic stress disorder (PTSD)

Motor reactivity: hypo and hyper

- Difficulties in initiating or sustaining voluntary and automatic movements
- Over-abundance of movement
- Involuntary repetitive movements, e.g. motor and vocal tics, which grade into obsessions and compulsions



- "My body is not who I am."
- "My body goes away."
- "My body has a mind of its own."



How do these experiences of self-advocates impact anxiety, and how can we respond helpfully?

In autism, sensorimotor processing and its connection to intentional action is:



- Partial
- Selective
- Intermittent

- Light level not as stated on bulb
- Light shines in different corners of room at different times
- Light sometimes turns on and off independent of button



What happen when we lose "connection to intentional action"?

- Actions and results may **not reflect intent** or choice
- The person may be seriously **misunderstood**



- Recall the **Croquet Game** in Alice in Wonderland
- What can it tell us about sensorimotor challenges?

Suppose your live game is
REALLY alive...



Do **anxiety** and challenges
to **sensory processing** go
hand in hand?



Research: "Sensory Over-Responsivity"
(SOR) connected with Anxiety

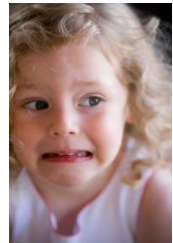
• 3 Theories

- SOR → Anxiety
- SOR ← Anxiety
- SOR ↔ Anxiety
(separate causes, but
amplify each other)



Research:

- Occupational Therapists more likely to diagnose **Sensory Over-Responsivity**
 - Recommend Sensory Integration therapy, sensory diet, etc.
- Psychologists more likely to diagnose **Anxiety Disorder**
 - Recommend Cognitive Behavior Therapy, medication



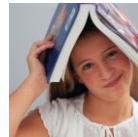
Anxiety Disorders and Sensory Over-Responsivity in Children with Autism Spectrum Disorders: Is There a Causal Relationship?
Shulamite A. Green · Ayelet Ben-Sasson J Autism Dev Disorders (2010) 40:1495-1504
<http://www.springerlink.com/content/t15371830474n060/fulltext.pdf>

Incidence



- **Anxiety disorders** affect more than 23 million Americans, and 10% to 15% of American adults
- **Sensory Over-reactivity** is estimated to affect **56-70% of children on the autism spectrum**
- Anxiety is common among children with ASD, but **incidence reports vary: 11% to 87%**
- SOR may affect 10-17% in the general population of children
- Rates are 3-24% in neurotypical children
- SOR has been linked to anxiety in children with ASD in at least 3 studies

"Intense World Syndrome"



- **Intense World Hypothesis:** core challenge of brain in autism is

- **hyper-reactivity** (**working harder** due to making **more but less efficient** connections)
- **hyper-plasticity** (heightened neural changes in response to experience, esp. **heightened memories** and intense responses to too many stimuli)

- "Hyper-functioning" brain processes lead to hyper-perception, hyper-attention, and hyper-memory



"The lack of social interaction in autism may therefore not be because of deficits in the ability to process social and emotional cues as previously thought, but because a subset of cues are overly intense, compulsively attended to, excessively processed and remembered with frightening clarity and intensity."



"Intense World Syndrome":
implications for treatment
and support

- **Medication**
 - Avoid meds designed to increase neuronal and cognitive functioning
 - Emphasize meds to calm and slow down brain function
- **Behavior support**
 - Emphasize positive, rewarding, comforting approaches
 - Avoid direct punishment, which may lead to a lockdown of behavioral routines
- *"It may well turn out that successful treatments could expose truly capable and highly gifted individuals."*

The Intense World Syndrome - an Alternative Hypothesis for Autism, by Henry Markram, Tania Rinaldi, and Kamila Markram. Brain Mind Institute, Ecole Polytechnique Fédérale de Lausanne, Switzerland. Neuroscience. 2007 November; 1(1): 77-96. Published online 2007 October 15.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518049/>

Exposure Anxiety: A response to the "intense world"?

A type of social anxiety common in autism

Does it arise when sensorimotor challenges have been misinterpreted, and not accommodated?

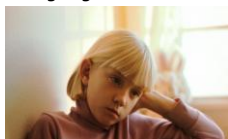


Donna Williams video:

<http://www.youtube.com/watch?v=bJNkYFuiv7g>

Exposure Anxiety: **examples**

- Cannot bear to ask for birthday gifts or specify a desired item
- Shies away from directly addressing a loved one (by name or as "Mom," etc.)
- Is pained even by GOOD attention for a job well-done
- "Watches" favorite TV show from another room
- Would rather withhold work and get grade of "0" than earn anything less than "A"



Can people with autism develop PTSD?



YES! Diagnoses often follow the use of:

- **AVERSIVES**
- **RESTRAINT**
- **SECLUSION**

*Some medical experts call PTSD among people with autism a **hidden epidemic**.*

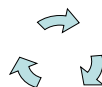
Effects of coercive techniques

- **Flashbacks**; intrusive memories
- **Hypervigilance**; "fight, flight, or freeze"
- Repetitive, **compulsive activity** patterns
- Reduced ability to control **emotions**
- Permanent **changes in brain**
- Loss of **skills**
- Reduced ability to pay **attention** and learn



These trauma responses can be **misinterpreted** as:

- Symptoms of the person's original disability
- Worsening of the person's original disability
- "Bad behavior"; willful noncompliance



The result is a "**vicious cycle**" of dependence on high-risk interventions.

How can we help?

1. **Medication** for anxiety

2. **Education**

- of the body
- of the mind

3. **Accommodation** for sensorimotor differences



Medication: what is the target?

- Research: 75% of people with ID/DD presenting psychiatric symptoms or behavior problems at a psychiatric facility had an underlying medical condition causing or contributing to it.

• Ruth Ryan M.D. (2011)



Meds often prescribed for people with autism:

- For continual, ongoing anxiety, selective **serotonin reuptake inhibitors (SSRIs)**:
 - Prozac
 - Luvox
 - Zoloft
 - Anafranil
 - Also used for OCD and depression
- For behavioral problems (anxiety has turned to fight-flight-freeze), **antipsychotics** sometimes still used:
 - Haldol
 - fluphenazine
 - chlorpromazine (Thorazine)
 - **Serious side effects** include sedation, muscle stiffness, irreversible tardive dyskinesia



Amygdala connection?

- Research: SSRIs used to treat anxiety in children may also reduce amygdala volume
- If an overactive amygdala contributes to **Sensory Over-Reactivity**, SSRIs might also reduce sensory challenges in autism

Anxiety Disorders and Sensory Over-Responsivity in Children with Autism Spectrum Disorders: Is There a Causal Relationship? Shulamite A. Green and Ayelet Ben-Sasson, J Autism Dev Disorders (2010) 40:1495-1504.
<http://www.springerlink.com/content/t15371830474n060/fulltext.pdf>



Caution!

- Symptoms that look alike may **respond differently** to the same medication, because their roots may be different
- Medication **doesn't change behavior**; it changes body chemistry
- Medication is **never a substitute for making needed changes** in a person's life
- Medication should be part of a **larger plan**
- All medications have **unwanted side-effects**



While some people respond well to meds for anxiety, often the best outcomes arise from:

- **Educating** body and mind
- **Fostering habits** and attitudes of personal awareness and emotional resilience



Educating the Body

- Sensory Integration therapy; Sensory Diet, de-sensitization, etc.
- Holistic physical disciplines: exercise, yoga, Tai Chi, etc.
- Activating "flow state"; play
- Music, dance
- De-escalation techniques
- Mindfulness



Sensory Integration Approach



- Highly **individualized** body activities
- Rich in vestibular, proprioceptive, and tactile inputs - areas where many children with dd are challenged
- Encourages the nervous system to **process and integrate sensory input** in meaningful ways
- Encourages **organization** at increasingly higher levels
- Goal: person will be able to **interact and adapt to the environment** more successfully

Holistic Physical Disciplines

- Growing interest in autism community
- Shares many goals, methods with SI
- Low-impact **physical exercise** + emphasis on **calming the mind** (meditation)
- Has been studied as intervention for pain, **stress, depression**
- Yoga is 6th most commonly used alternative therapy in the United States



Activating "Flow State"; Play

Play: "A state of experience in which the actor's ability to act matches the requirements for action in his environment. It differs from **anxiety**, in which the requirements outnumber the ability, and from **boredom**, in which the requirements are too few for the ability level of the actor."

Mihaly Csikszentmihalyi



*"The opposite of play is not work. It's **depression**."*

- Brian Sutton-Smith, folklorist



*"In play a child always behaves **beyond his average age, above his daily behavior**. In play it is as though he were a head taller than himself."*

- Lev Vygotsky, psychologist

*"Play is training for the **unexpected**."*

- Marc Bekoff, biologist



Music and Dance

- Can be used to **communicate and express emotion** - especially when other channels of expression are compromised
- Music and dance therapy can help relieve psychological, emotional and **stress**-related conditions



De-escalation Techniques

What is in your "Prevention Kit"?

- **Plan ahead** to de-fuse "Fight-Flight-Freeze"
- Avoid complex sensory input: **NO talking!**
- **Back off**, give space, take time
- Use **breathing** control techniques
- **Model** needed actions; use visuals or hand signals



Mindfulness: bridging body and mind

- Mindfulness -- "**paying attention** in a particular way: on purpose, in the present moment, and nonjudgmentally."
(Jon Kabot-Zinn, MD, UMass Medical School)
- NIH study: **pain-related med use decreased**, activity levels and feelings of **self-esteem increased**
- Techniques help focus and **control rambling thoughts**, teach **calming use of breathing**
- Increasingly used by people with autism!



Educating the Mind

- **Psychological** approaches combining verbal and experiential components
- **Tools** for making the physical and social environments clear
- **Reframing**: Positive uses of "hypervigilance" in recreation, employment



Psychological strategies

- Teaching positive **self-talk**
 - Positive interpretations, words, imagery created and practiced
 - Empowerment; confidence-building
- **De-sensitization**; "exposure therapy"
 - Activating anxiety/fear system under safe conditions to teach new responses
 - May utilize play activities, drama, scary movies, stories, amusement park rides, etc.
- Routines for facing **the unexpected**
 - Advance teaching and practice of calming phrase, activity, thought, response
 - Planned exposure to non-negative novelty



Cognitive Behavior Therapy (CBT)

- Recent studies suggest usefulness for **treating anxiety** in autism
- **Components**:
 - psychoeducation
 - cognitive restructuring
 - self-talk
 - relaxation
 - exposure to feared stimuli
- Some therapists adapt CBT by simplifying cognitive aspects, emphasizing **concrete aspects such as relaxation and controlled exposure**



Tools for making the physical and social environments clear

- **Lists**, maps, charts (for home and school)
- **Social Stories** (see Carol Gray's books, web site)
- **Pictures, visual cues** (in strategic places)
- **Autobiographical materials** (photo albums, collages, bulletin boards, collections, personalized articles of clothing such as t-shirts, merit badges on sash, etc.)



Reframing: "vigilance" has many positive uses!

- **In the home and school**
 - Safety monitoring
 - Scheduling, reminding
 - Neatness
 - What else??
- **In recreation**
 - Score-keeping; timing
 - Knowing the rules
 - Computer games
 - What else??



- **On the job**
 - Medical professions (e.g. reading x-rays)
 - Data processing
 - Book-keeping
 - Inventory
 - Proof-reading
 - What else??



Accommodating Sensorimotor Differences

Accommodations are strategies and supports that help a person **overcome or "work around"** sensorimotor differences. They must be personalized and able to be changed as needed.



When we accommodate differences we must start with the assumption that **differences are okay.**



Types of Accommodations



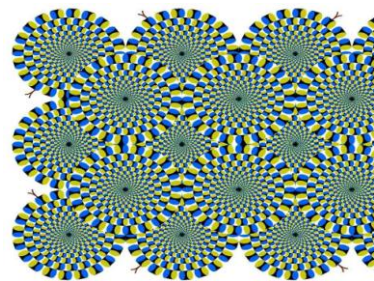
- ENVIRONMENTAL
- SELF-REGULATORY
- INTERACTIONAL

Environmental Accommodations



- **Sound:** avoid sudden, loud, reverberating noises; maximize preferred rhythms, music
- **Light:** too bright or flickering light may cause anxiety; soften levels, reduce glare
- **Arrangement:** avoid clutter, confusing patterns; maximize visual displays for tasks, activities
- **Smell:** certain smells may overwhelm; preferred smells may calm, aid in identification of a beloved person or place, etc.
- **Texture:** certain textures of food, clothing, surfaces may be distracting and even painful

Awareness:
what do you see?



Self-Regulatory Accommodations



- "Sensory Diet"; manipulatives for calming and sensory **feedback**
- Earphones, earplugs, tinted glasses etc. to **reduce sensory overload**
- **Deep pressure** via weighted vests and blankets, trampolines, swimming/diving, brushing etc. for calming, proprioception (body feedback)
- Possibilities limitless **but** must be individualized and not "done to" the person

INTERACTIONAL ACCOMMODATIONS involve adjusting:



- Rhythm
- Movement
- Touch
- Space
- Communication (channels, rate, wait time, length, content)
- Emotional expression and demands
- Power relationships

Accommodations for Emotional Expression and Demand



- Presume depth and **sensitivity** of emotions
- Monitor and limit the person's emotional load; **buffer** against
 - "Too much" good or bad feeling
 - Uncontrollable escalation of a feeling; becoming stuck in a feeling

- Help the person to **self-regulate** and self-report; respect need for breaks and "down time"

- Use **redirection, distraction, indirect** reference to avoid:

- Performance anxiety
- Exacerbating motor and vocal tics, compulsions and obsessions



Accommodations for adjusting power relationships

*Many programs and interventions have been built on the belief that people with disabilities have **too much power and control**, so our response should be to **take their power away**....*



*What would happen if we assumed the **opposite**:*

- > That much of the behavior that gets people in trouble is a response to **LACK of power, fear, and anxiety**, and
- > That the solution is to support people to have **MORE power and control**?



The Wrap-Up!

- What will you do more of?
- What will you do less of?
- What will you try that's new?



Thank you for coming today!



For additional information or questions
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